Presenter: Mysti Geiger GC and Carol Lustig NP ACGN

Authors: Meghan Underhill-Blazey; Ashley Hendershot; Carol Lustig; Laura Kent, Mysti Geiger, Art DeCross

Title: ASSESSMENT OF PATIENT REPORTED NEEDS, PREFERENCES, AND EDUCATIONAL OUTCOMES AFTER ATTENDING AN ONLINE SUPPORT GROUP FOR PERSONS WITH LYNCH SYNDROME

Abstract

Lynch Syndrome (LS) is characterized by an increased risk for cancers of multiple organ sites, such as colon and endometrial cancers, and others. A diagnosis of LS is associated with complex medical recommendations for cancer screening and prevention that may cause stress or worry. Support groups can provide educational and information support to attendees to help navigate the complexity of cancer early detection, prevention, and treatment in the context of LS. A support group for patients and caregivers/family/support persons of patients with LS was started in 2019 at the Wilmot Cancer Institute Hereditary Cancer Program at Pluta Cancer Center. This group is led by the programs nurses and is supported by the departments' social worker. It is held four times a year over a Zoom platform. A formal educational session is held with a chance for discussion, reflection, and interaction between participants. Here we with further describe the support group model and report results from a survey to assess participants experience with the support group to improve and further develop the offerings moving forward. The survey is a thirty-five item self-reported electronic survey assessing demographic information, attitudes and beliefs, satisfaction, worry, self-efficacy, and open-ended items asking for suggestions for content. Eligible participants were those who had previously taken part in the LS support group. Surveys were sent by email and the response rate was 82% (n=9), three of which had previously attended a support group. Of the participants six identified as female, eight white, and seven married. Four participants had never had cancer and seven responded that they had previously had cancer and/or actively have cancer. Seven unique zip codes were represented. Overall, participants were satisfied with content and format of the groups, felt that information was useful, and felt-confident that they could apply information learned. Participants suggested a focus on how to identify a care team with Lynch Syndrome experience, more information about genetic testing, risk for other cancers other than colon cancer, lifestyle interventions such as diet and exercise or reducing alcohol or tobacco use, as well as stress reduction techniques. In conclusion, the support group was useful for those who attended. Future work should aim to increase attendance and also tailor content based on feedback obtain.